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DEMENTIA CARE IN INDIA: ISSUES &PROSPECTS

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ABSTRACT

Dementia care may not be equivalent to conventional old age care and should be given attention separately from any other form of old age care. In the devalued field of care for elderly people, caring for those with dementia has been seen as an unrewarding job especially in developing country like India. Because of the rapid aging of India's population, there has been proportionate increase in prevalence of the dementia leading to emergence of major socioeconomic challenges in dementia care and care giving. Lack of community awareness, rapid erosion of family support and poor government initiatives on these issues have been the well recognised drawbacks of dementia care in this country. This led us to review and analyse the current social and health care scenario with limited available evidence and literature pertaining to dementia care with special emphasis on issues facing dementia care and their prospects.

Source of Articles: Google Scholar, Pub Med

KEYWORDS: Dementia, Dementia Care, Elderly, Dementia Care in India

INTRODUCTION

The population aging in developing countries has huge impact on demographic shift of many chronic disease conditions of old age. Dementia, one of the most significant degenerative disease of old age has been given the least visible public health importance in Indian subcontinent, where the prevalence of dementia is rising in proportion to its increasing aging population. Dementia India Report 2010 gave a gross estimation of about 3.7 million Indians were with Dementia and the societal cost of dementia was about 14,700 crores in Indian Rupees[1].There is a differential proportion of demented people in different regions and varies from rural to urban areas. Prevalence of dementia using survey diagnosis or clinical diagnosis of DSM IV or ICD 10 reported from Indian studies amongst the elderly range from 0.6% to 10.6% in rural[2,3,4] areas and 0.9% to 7.5% in urban[2,4,5,6,7] areas. Dementia; so far widely accepted as non curable condition has to be managed at various levels to prevent the dependency on their caregiver. India, where most of the health care resources and man power are diverted to the management of communicable diseases, dementia care obviously remains the least priority. There has been immense trial and bio-medical research to find out the causes and cures of Alzheimer's disease, but much less attention has been paid to the care of those suffering from these disorders (patients and families). Globally it has been acknowledged that lack of awareness about the disease exists among patients as well as healthcare staffs[8], and similar scenario is prevalent in developing countries including India. Social stigma of having a disease of forgetfulness and common notion among people about dementia as a process of normal aging are considered the main barriers of the dementia care[9]. In addition to these, poor campaign and lack of administrative policy framework on the issues multiplies the problems of dementia care. In the current Indian scenario, the existing primary health care system is ill prepared to provide dementia care, therefore most dementia cases are managed in specialist or tertiary care units[10]. Home based and

community level of care giving are not developed at present due to variety of reasons. The option of long term care is limited and inadequate for dementia related disabled individuals. In this article, we analyse the current issues and prospects pertaining to all modalities of dementia care for future direction.

Home Based Care

Considering India's social structure and culture, immediate family members are the main carers of older people in home. But this strong cultural tradition of giving respect, bearing the financial need and taking care of older members of family are changing very fast. Multiple reasons are attributable to this changing trend. Though 80% of older people live in rural India[11], but urban migration of younger family members and change of family structure from a joint to nuclear family isolate these older people with increasing need of care [12]. Care giver strain was interestingly found to be high even in families with large households where contrary is expected[13]. There is no uniformity of quality and patterns of elderly care in Indian family system in which gender difference in the availability and provision of care is common[14]. Male elders and those having bank savings or assets are likely to receive more care and attention in their family. Often, the financial need of all family members rest on one adult male member of the family and major household work including child care are solely performed by one house-wife, the daughter-in-law of the family. Daughters-in-laws are expected to fulfil the role of the caregiver for their husband's parents. This puts enormous pressure on main earning member of family and main care giver of older parents. In that scenario, demented member of the family with a functional decline or behavioural problems is likely to complicate the whole family situation. Very often this may lead to conflicts and disharmony in the family, finally may turn into older abuse and neglect. Older participants in "10/66 Dementia Research Group Studies"[15] corroborated this view; some said they were not happy in their child's home either because of a son's illness (often alcohol dependency) or abuse and neglect. Children were furthermore `authori-tative' and wanted things done their way. With time the reliability and universality of ideal family care system in India has been eroded[16].Need for 'caregiving' defines 'dependency'. Quantifying dependency is difficult and complicated. One method of quantifying the 'intensity of need for help' is to define the length of time during which a person can manage without human assistance – the so-called 'interval of need'[17]. According to this, People who need help all the time (such as supervision of someone with dementia who falls or wanders) are included in a category of 'intensive care needs'. The dependency ratio in India is as high as 9-12%[18]. Care of demented people with intensive care needs will definitely be additive to home based and community level care of older people. In urban India home based support and care of aged member of family is no more the sole responsibility of traditional house-wives, as more and more female family members are taking up employment outside their homes to supplement the family income. Therefore, home based care, though widely believed to be best and affordable for patients with dementia seem practically not feasible with changing dynamics of Indian Family. Very soon there will be high need of assisted living facilities or institutions or some form of community support system for long term care of demented people with 'intensive care need'.

Institutional Long Term Care

With aging society and increase prevalence of dependency more and more older people will be requiring some sort of institutional long term care all over the world. As per the U. S. Department of Health and Human Services, four out of every ten people who reach age 65 will enter a nursing home at some point in their lives. About 10 percent of the people who enter a nursing home will stay there five years or more [19].

Assisted living facilities or institutions which provide long-term care are few in India and the exact data on number and quality of these elderly care facilities are not available. As per "Help Age India" statistics 2009 [20], there are

1276 old age homes in India. 650 homes are free of cost while 188 old age homes are on pay and stay basis, 146 homes have both free as well as pay and stay facilities. Detailed information is not available for 292 homes. 118 homes are exclusive for women. Paid and private run facilities are expensive and are usually located in urban or semiurban areas. A majority of the old age homes are concentrated in the developed states of the south and western parts of India. In a country like India, where majority of older people live in rural India with low and middle income family, these limited institutional long term care facilities are either not easily accessible or not affordable to needy aged people and their family members. Often these long term settings do profiling of patients on the basis of mental health for admission because intensive need of care giving is involved in these patients. Therefore, older patients with dementia are the neglected most to avail these provisions.

Hospital Based Care

A cute care services are usually designed in a way to address patient's acute medical problems. The primary aim is to provide fast and effective services in assessment, diagnosis, intervention, cure, if possible and discharge. People with dementia attend acute care centers for the same reasons as older people generally. Studies showed about 43 percent of people with dementia were admitted to hospitals with pneumonia and urinary tract infection and 42 to 48 percent hospitalised patients aged 70 and more had dementia[21].

Emergency Departments(ED) are commonly the first point of contact for older patients coming into hospitals. The busy environments, time constraint and lack of elderly specific orientation on the part of staffs and treating doctors are the well recognised hurdles in treating older patients in ED. It is seen that Patients with dementia and their carers find this situation the most challenging to communicate with the Emergency staffs[22]. Someone needing additional time and support, whose behaviour can affect ward routines, can be perceived as disruptive or difficult by the health care providers[23]. Even after hospitalisation in conventional medical wards, disease-specific pathways of care are not always conducive to meeting the needs of people with a dementia[24]. Almost nine out of ten nursing staff respondents in the Alzheimer's Society (2009) study identified that working with people who have dementia is quite or very challenging: particularly in demented patients with behavioural problems[25]. In India there is no separate facility available in Emergency Department either for older patients or for the patients with specific problems such as dementia. Health care attendants, nurses and even treating physicians are not trained to deal with demented patients. If general hospitals are to provide effective care for people with dementia, all staff and services have a role to play.

Environmental modification requires systematic planning. The commitment of hospital management to making changes and staff contributions are essential[26]. A part or cubicle of medical ward has to be dedicated to patients with dementia. This component of ward must be designed accordingly with effective use of lighting, colour contrast, noise limiting measures and clear orientation cues. Large clear signs, particularly to toilets, and clocks showing the correct time can aid orientation. In the absence of this, a clock beside a person's bed can be helpful. Some aspects of hospital environments, including mirrors, pictures and cluttered notice boards, can be confusing for people searching for their reality.

There is huge requirement of specialised geriatric care services in General hospitals and in all tertiary care centers. Even the geriatric OPD should have provision of dedicated memory clinic for this group of patients. Training of staffs, residents, Post graduate program in Geriatric Medicine and undergraduate teaching curriculum in Medical schools on various aspects of geriatric medicine including dementia care will definitely pave the way further in that direction.

Government Initiatives and Community Care Giving

The Ministry of Health & Family Welfare of India has launched "National Programme for the Health Care of Elderly (NPHCE)" during 11th Five Year Plan period to address various health related problems of elderly people[27]. The aim of the NPHCE is to provide separate and specialized comprehensive healthcare to the senior citizens at various level of State healthcare delivery system including outreach services. The major components of the NPHCE during 11th Five Year Plan were establishment of 30 bedded Department of Geriatric Medicine in 8 identified Regional Medical Institutions (Regional Geriatric Centres) in different parts of the country and to provide dedicated health care facilities in District Hospitals, CHCs, PHCs and Sub Centres in 100 identified districts of 21 States. In this ambitious government initiative, more emphasis was put on to impart awareness at the sub center and primary health center on dementia care including other aspects of elderly health care. There is a provision for domiciliary visit by health care workers for attention and care to home bound/bedridden elderly persons and provide training to the family care providers in looking after the disabled seniors. Therefore, we need to integrate dementia care component with this and also equip the outreach services to support home based care for the people with dementia. Training of primary health care medical officer in mental health care has been a success in achieving adequate skills in dementia care in Indian settings[28].

The impressive results of community participation in dementia care have been observed in southern parts of India by various studies. Even simple community based day care services such as recreational activities, occupational therapy, counselling services, medical services and a mid day meal had shown significant reduction in psychiatric morbidity and improvement in quality of life scores in older subjects[29]. A community care program for older people with functional impairment "Pariraksha" a joint venture by the District Panchayat (local government) in Malappuram in Kerala state, which offer support and guidance to all chronically and incurably ill patients in the district, has been highly successful in community care giving for disabled elderly [30].

Volunteers and other partners from the local community, those involved in such type program should be trained on the various aspects of dementia care to make these people community independent despite being suffering from incurable disease. Caring the carer is one of vital component of dementia care support system. Care givers stress always has negative impact on mental and physical health of patients as well as carers. The Indian network of "10/66 Dementia Research Group" developed a community based intervention programme[31]. The intervention includes provision of information and education about dementia, sustained carer support and guidance in managing symptoms of dementia. Intervention trials from India reported highly promising results.

Rehabilitative Mental Care

Rehabilitative care in the different stages of dementia is a vital need in managing the behavioural symptoms and other associated physical limitations, as there are no complete curable or remedial measures available for dementia. Indian data about research and trial on the beneficial effect of physiotherapy and occupational therapy interventions on dementia is limited, though the positive effects of these modalities of rehabilitative care have been well documented in various studies internationally[32,33]. An occupational therapy protocol[34], a pilot study[35] followed by a randomised controlled trial[36] for dementia by Prakash et. al from All India Institute of Medical Sciences, New Delhi, India have showed that specific occupational therapy intervention program is very effective in increasing the mood, functionality, physical performance and overall quality of life of the cognitive impaired elderly.

Physiotherapist and occupational therapist, working under NPHCE program at CHC level should have training and orientation in that direction with a view to improve functionality and quality of life in these patients.

Prospects

A lot has to be worked out to achieve some sort of ideal dementia care in this country. Keeping in view of socioeconomic situations and demographic vastness of this subcontinent, home based care is the first priority in dementia care. All efforts are to be given to identify patient's primary care giver in the family, who is to be trained in basic dementia care and simultaneously she or he should be taken care of caregiver stress. Sustained guidance and monitoring is needed from community service providers. Inclusion of dementia care component in the ongoing NPHCE Program will strengthen home based as well community based support for older patients. The role of therapist in dementia care is extremely vital in ameliorating behavioural problems, improving functionality and quality of life; hence government and policy makers should recruit more numbers of therapists to serve at primary care level. At the tertiary care level, Emergency department and ward services should be separate for older patients, so that patient with dementia will have special attention from the staffs and health care workers. It's an urgent need of time to increase the number of post graduate courses and inclusion of course curriculum on geriatric medicine for undergraduates in all medical schools. Lack of adequate and elder friendly long term care facilities in India is always a huge concern. Government, NGO and private sector should take active steps to increase, improve and maintain the long term care facilities for older people. Involvement of corporate health care and health care insurance sector in this endeavour will enhance the overall elderly health care including dementia care in the long run.

Competing Interests

All the authors have seen the final manuscript and approve it for submission. The authors have no competing interests in the publication of this manuscript to declare.

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